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ABSTRACT

This project summary focuses on the emerging social policy trend toward providing services which assist families in providing home care for their developmentally disabled family members, rather than encouraging out-of-home placement. Three project objectives encompass the issues of innovative approaches to family involvement in caring for disabled relatives, family financial planning for future care, and countering fiscal disincentives toward in-home placement. Objectives were achieved through a national survey of knowledgeable professionals, a literature review, preparation of five concept papers, and a working conference on family-based care. Among major findings were the identification of novel approaches to service design (initiation of statewide family support programs, utilization of private sector resources, utilization of tax policy, initiation of a national family allowance system), carefully worded trust arrangements as an effective means of financial planning, and an understanding of the effect of extraordinary health care costs on present placement decisions. The 13 recommendations which conclude the summary report reflect an overriding commitment to replace past biases in social policy and professional judgments that once favored out-of-home placement of developmentally disabled persons. (JW)

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FAMILY CARE FOR PERSONS WITH DEVELOPMENTAL DISABILITIES: A GROWING COMMITMENT

EXECUTIVE SUMMARY

May 20, 1985

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EXECUTIVE SUMMARY

Families of persons with developmental disabilities face a variety of dilemmas and choices regarding the care of their family member with disabilities in the long term including the choice of whether or when to place their relative out of the home. Such choices and the considerations that precede them are heavily influenced by public policy at the state and federal level. Unfortunately, such policy often discourages rather than encourages continued care in the family.

Recent policy discussions, however, have focused increasingly on the creation of a range of measures to assist families who provide home care. This growing dialogue offers great promise for these families and is the focus of this report.

Project Objectives

The primary intent of this project was to explore factors that constrain family involvement and to identify new and improved means for overcoming such barriers. To achieve these goals, the following three objectives were set:

- To identify new and creative ways of involving families in caring for their relatives with developmental disabilities and to determine the barriers to growth and acceptance of these new approaches;
- To identify new approaches for encouraging families to plan financially for the future of their relatives with disabilities; and
- To examine the fiscal incentives and disincentives that influence parental choices regarding the placement of family members with developmental disabilities and to identify innovative ways of countering incentives that favor out-of-home placement.

Approach Taken

These objectives were achieved through a variety of activities including:

- The solicitation of information from knowledgeable officials in the 50 states. This national survey provided information on the status and character of family support programs around the country;
- The preparation of a literature review that presents state-of-the-art information on family support theory and practices. Information was collected through a search of library materials and by soliciting information in the publications of 20 relevant organizations;
- The preparation of five concept papers related to family based care. The first paper presents an overview of the goals and purposes of family support services. The second presents a parent's perspective on the topic while the third offers the perspective of a person with disabilities. The fourth paper elaborates on current options for family support policy. Finally, the fifth paper examines the potential future directions for such policy; and
- The conduct of a working conference on family based care. This conference was attended by approximately 40 persons representing a wide range of interests, perspectives, and knowledge.

A Crucial Consideration: The Needs of Families

The presence of a person with developmental disabilities in the home can present the family with a variety of extraordinary problems. For many families the initial recognition that a severe disability exists presents an immediate crisis that grows into a life crisis. Several of the problems families can experience include:

- Adverse reactions to the discovery that a family member has a developmental disability including a sense of shock or numbness, denial, grief, shame, guilt and depression;
- Chronic stress;
- Social isolation resulting from perceived negative attitudes and/or rejection by kin or neighbors;
- Financial costs or lost opportunities for employment, career advancement, and education;

- Extraordinary time demands involved with providing personal care to the family member with disabilities and teaching this person adaptive living skills;
- Difficulty with physical management (e.g., ambulation, lifting, carrying) and in handling socially disruptive or maladaptive behavior;
- Difficulty in undertaking normal family routines such as shopping and house cleaning or in finding ample opportunity for recreation;
- Lack of the skills needed to cope with the potential medical emergencies and/or to teach necessary adaptive skills;
- Marital discord stemming from the ongoing burden of long-term care; and
- Absence of needed community services to complement and enhance the care provided in the home.

In addition, two other factors must be considered. First, the needs of persons with developmental disabilities will change over time as the individual progresses from one developmental plateau to the next. Second, as parents grow older their capacity to provide care changes. Moreover, in addition to meeting daily life requirements, parents must eventually give thought to how the needs of their family member with disabilities can be met after they can no longer provide care.

The above review suggests that in addition to the direct care services required by the family member with disabilities the family also needs support services to enhance its caregiving capacity. Participants at HSRI's working conference on family support noted the following problems with the way such services are currently provided.

- Lack of individualization of services received. Because family situations are unique, services must be flexible enough to accommodate each family's individual needs. Existing family support services, however, are often designed with an insufficient capacity for such flexibility, resulting in an unsatisfactory match between services and family needs;

- Insufficient control over services received. When available support services do not match family service needs, families often have little leverage to modify the services they are offered;

- Inadequate information regarding the present and future needs of the family member with disabilities as well as the implications these needs have for family care providers. The need for such information begins at the time of birth of the person with disabilities and continues throughout his/her life;

- Shortage of time to care for the person with disabilities, perform normal household routines, undertake productive activities such as attending school or working, and cope with other aspects of one's personal and familial life;

- Insufficient number and range of direct services for the person with disabilities. For persons with disabilities of school age this often includes the availability of habilitative activities during evenings and/or weekends. For adults with disabilities this can involve a need for daily vocational instruction, alternative community living arrangements, and a variety of age-appropriate social and recreational activities;

- Lack of instrumental and environmental supports. These supports include proper adaptive equipment for the person with disabilities as well as the provision of a living environment that is barrier free for both the person with disabilities and the family caretakers;

- Inadequate specialized health care to meet extraordinary needs regarding medical and/or dental care;

- Needs for a support network for and led by parents to provide informal support, share information, and overcome the social isolation many families experience; and

- Insufficient means to ensure the future well-being of the person with disabilities. This issue pertains primarily to guardianship and financial planning.

These problem areas are not and cannot be ranked in importance. Each family has a unique cluster of needs and would critique the availability and quality of services differently depending on their circumstances. In fact, many families may have problems that do not appear on the above list.

This list, however, suggests that though families are willing to

provide long-term care to their members with disabilities, they need additional supports that are tailored to their unique circumstances. The challenge before us, then, is to translate this need into an effective system of supports that recognizes the therapeutic as well as human needs of families and of persons with developmental disabilities.

Major Findings by Project Objective

Objective 1: To identify new and creative ways of involving families in caring for their relatives with developmental disabilities and to determine the barriers to growth and acceptance of these new approaches.

Novel Approaches to Service Design

During the course of the project numerous novel approaches to service design were examined including: 1) initiation of statewide family support programs, 2) utilization of private sector resources, 3) utilization of tax policy, and 4) initiation of a national family allowance system.

Initiation of statewide family support programs. Ten years ago, very few statewide family support programs existed. At present, however, nearly 25 states operate what could be termed "extensive" programs, suggesting a growing commitment to initiate policy that supports, rather than supplants, family efforts. These programs complement other community based programs for persons with disabilities and their families such as those offered by the public school system, universities, advocacy groups, and the private sector. The primary goals of emerging statewide programs are: 1) to prevent unnecessary out-of-home placements, 2) to make it possible for families to have their member with a disability return home from an out-of-home placement, and 3) to enhance the capacity of families to provide care.

Analysis of 22 of these programs reveals significant variance along several key dimensions including the number of persons served, eligibility criteria, appropriation levels, services provided or permitted, and means of administration. These findings are complemented by information amassed during other project activities and clearly demonstrate that no consensus has emerged regarding the "best" means of operating a family support program. The approaches taken vary considerably and suggest a need and willingness to design flexible programs and to consider novel approaches.

Eight approaches with significant potential are those that:

1. Empower families and persons with developmental disabilities.

   An underlying theme of family support pertains to the role that families can play in the provision of care. A primary finding of this project is that family support programs should be designed in ways that:

   - recognize the family's underlying commitment to care for their family member with a disability;
   - embrace practices that promote, not discourage, increased family independence from the formal service system;
   - take seriously the view of the family and the person with disabilities with regard to how services should be designed and rendered; and
   - treat the person with developmental disabilities not as an passive recipient of services but as someone who should participate in his or her own care to the extent feasible in order to develop as an informed self-advocate.

   When these principles are used to guide program design, the family support system, while based on the aggregated need of all service consumers, is ultimately accountable to individual consumers. As such, it empowers families and persons with disabilities on two levels:

   - Systems level: Service consumers have significant input into the substance, administration and planning of services; and
   - Family level: Service consumers have some control over the services they receive. This suggests that flexible multiple service options should be available and that

families and/or persons with disabilities be able to select services from a comprehensive service menu.

In essence, the eventual goal of the system is to equip service consumers, whether they are family members or persons with developmental disabilities, to provide and/or obtain competent care, not to ensnare them in bureaucratic mazes and to make them dependent on professional judgements.

2. Provide families with multiple service options.

No two persons with developmental disabilities or two families are alike. Considerable variation exists regarding disability types and severity, family characteristics and resources, and family perceptions of the caregiving situation. Moreover, these factors are not static but evolve with time. These considerations suggest that responsive family support programs must permit a wide array of services and encourage each family to select those services that are most appropriate for their needs.

3. Make use of cash assistance programs.

Many states presently operate cash programs that provide families with money to offset the costs of providing care. These programs generally extend greater control to families over the services they receive. Moreover, even in states where systems of free in-kind supportive services also exist, cash programs allow parents to complement whatever services are available with others as needed. In essence, they represent a cost-effective and flexible means for states to accommodate the unique needs of individual families.

4. Make use of existing mechanisms for modifiying Medicaid eligiblity criteria.

For years, the income eligiblity standard pertaining to Medicaid has acted as a disincentive to family-based care. Under present deeming rules, the income of parents is treated as though it were available to the Medicaid applicant as long as s/he is living with the family and is under age 18. If the level of parental income surpasses the income eligibility criteria, the person with disabilities fails to qualify for Medicaid. In contrast, if the person with disabilities lives away from the family (e.g., in an institution or community home), parental income and resources are no longer considered available to this person. Thus, given that the person with disabilities satisfies the eligibility criteria s/he will receive Medicaid benefits. As a result, this policy encourages parents either to place their family member with disabilities out of the family home, pauperize themselves to become Medicaid eligible, or forego needed medical coverage altogether.

The federal government has initiated at least three programs to ameliorate the several problems associated with the

Medicaid program. They include: the Community-Based Waiver Program (Public Law 97-35; Section 2176), the Model Waiver Program, and Section 134 of the the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA). At present, 33 states make use of at least one option, while five make use of two. Seventeen states have not made provisions for utilizing any of these three options for countering present means income eligibility criteria associated with the SSI and Medicaid programs.

5. Utilize evolving computer technology.

Greater emphasis could be placed on using computer technology to assist parents. On a local level, computerized information networks could be established to encourage greater cooperation among families. For instance, listings of persons that could assist parents could be maintained and shared with parents as needed. Such persons could include qualified respite providers, building contractors experienced with removing home barriers, dentists or doctors who understand the special needs a person with disabilities may have, and other professionals whose services families may require. In addition, such networks could maintain information on special equipment or toys parents may wish to share or exchange with oneanother.

Similarly, on a state or national level existing information systems, such as Project SHARE, could be utilized to foster more effective means of providing families with information pertaining to state-of-the-art instructional practices, useful state and federal tax relief programs, and novel private sector initiatives. This type information would help keep parents aware of what is available on a broader systems level as well as promote greater cooperation among caregiving families around the country.

6. Encourage development of parent-led mutual help organizations.

Encouraging the development of parent-led mutual help groups will complement efforts to structure family support programs within a family empowerment model. Examples of such groups include those offering ongoing social support and advocacy training, and others involving joint estate planning. In addition, the need for providing support and information to other members of the immediate (e.g., siblings) and extended (e.g., grandparents) family should not be overlooked.

7. Make use of existing resources and facilities.

Developing family support systems does not necessarily imply a need for funding an entirely new and separate service system. Much can be done to build on existing resources. For instance, greater use can be made of public school facilities, community college campuses, community centers, church facilities, and other existing sites to serve as day care centers, recreational sites, evening respite centers, or training sites for persons with developmental disabilities and their family members.

Similarly, initiatives must be undertaken to encourage improved coordination between existing service providers such as public school teachers, family support providers, case consultants, medical care staff, vocational instructors, and specialized therapists (e.g., speech and physical therapists). None of these providers should work in a vacuum since the family must interact with each. Thus, care must be taken to coordinate the level, type, and content of services to maximize their combined effect. This issue takes on extraordinary importance during "transition periods" in the lives of the person with disabilities and his/her family (e.g., when the person with disabilities "ages out" of the public school system, when parents grow too old to provide home care, when the person with disabilities desires to move away from his/her family).

8. Evaluate the efficiency and effectiveness of services provided

The purpose of program evaluation should not be to justify ongoing funding for family support but to determine what types of programs are most efficient and effective. Ideally, such research should be tied to specific models of family interaction. As relationships between family dynamics and the provision of family based care are understood, systematic programs could be designed to embellish family interactions concerning the family member with disabilities and improve the overall caregiving environment.

Moreover, such research can be used to help coordinate multiple funding sources or service providers. In the future, family support services will likely make use of multiple funding sources (e.g., the private and public sectors) and administrative formats (e.g., supportive services and cash programs). With experience and systematic study, the most beneficial formats may emerge. For instance, it may be found that certain services are best funded through the public sector. Likewise, the most beneficial administrative formats may also vary by service. Some services might best be operated as cash programs. In contrast, other services might best be provided as free supportive services. In addition, it may be determined that certain system functions should be primarily state-directed, including needs assessment and evaluation, oversight, resource organization, and fund raising. In essence, research efforts must be directed at documenting the most efficient, effective, and equitable means for delivering family support services.

Utilization of private sector resources. Certainly, private businesses cannot be expected to carry a major part of the burden for family-service initiatives. Businesses have, however, shown some interest in allocating resources to complement services offered

through the public sector. This interest could be promoted by: 1) establishing systematic procedures for businesses to contribute money to existing family support programs; 2) encouraging initiation of additional employer sponsored cash or fringe benefit programs for employees who have family members with disabilities; and 3) encouraging businesses to offer certain family support services of their own to complement existing public programs.

This latter suggestion is especially relevant to the health care industry. Government should act to encourage private health insurers to underwrite coverage for home health care. This could involve mandating that such coverage be made available as part of individual and/or group risk plans and establishing tax policy that provides incentives to insurers for providing such plans. It must be understood that the provision of suitable and affordable health care for persons with disabilities is an essential element of any family support system. To achieve this end, government and private insurers must work together as partners so that needed medical care will be within reach of all families.

Utilization of tax policy to support families. Though numerous incentives to encourage family based care could be provided through the tax system, these incentives must be viewed in light of their efficiency, effectiveness, and fairness. Using tax credits, tax exemptions or specialized tax relief in support of individual families is somewhat questionable due to problems associated with: coordinating multiple levels of government, enforcing regulations, estimating costs in lost government revenue, establishing equitable programs, and making programs easily accessible to families. Moreover, it should be understood that reducing potential tax

liability is akin to providing parents with publicly financed cash assistance. This being the case, government officials must decide if the most desirable means for providing such assistance is through tax policy. This point grows especially salient in view of the current trend to establish statewide family support systems that approach the task in a more straightforward and systematic fashion.

Initiation of a Family Allowance System. Following the lead of numerous other countries, the federal government can choose to support children with or without handicaps through a cash allowance program. Such a program would provide all families with a periodic cash stipend for each child living at home. An allowance program could be established by tranferring monies from several presently existing income maintenance programs. At present, 69 nations administer family allowance programs including 28 European, 24 African, 2 Asian, 3 Middle East, 10 South American, Austrailia, and New Zealand. For instance, families in Bolivia receive a housing allowance, birth grant, nursing allowance, burial allowance, and monthly cash payments.

Barriers to Initiating Novel Approaches

Three major barriers confront those charged with initiating family support programs: attitudinal barriers, demographic trends, and administrative uncertainties.

Attitudinal Barriers Three types of attitudinal barriers constrain the development of family support services. First, there is no consensus regarding the role of the family in the provision of care. Some professionals discount the family's capacity for making sound decisions about the welfare of their child or adult with disabilities. This presumption of incompetence in turn leads to

recommendations for out-of-home placement as a matter of course.

Second, many families are themselves caught in a crossfire of conflicting interests and social role expectations. On one hand, current lifestyles emphasize independence, self actualization, and employment outside the home for women. Running counter to these values is a renewed interest in family-based care and a need for one family member to remain at home to provide care. Consideration of these contradictory perspectives can create for many families an unsettling sense of ambivalence regarding their future and the future of their offspring with disabilities.

Third, society has not reached consensus over the public's role in private family affairs. This dilemma is both moral and political. Some believe, for instance, that parents themselves are responsible for any problems they encounter in bearing children and that the public should play a limited role in family affairs. This position suggests that public sector dollars should not be used to pay for care provided by families to their family member with disabilities. In contrast, others believe that the presence of a person with a disability in a family should result in increased public involvement because of the special needs of family caregivers and persons with disabilities. Such involvement includes provision of support services to help the family live a life that is as close to normal as possible.

The political reality is that far more persons with disabilities live at home with their families than in alternative residential arrangements but that the great majority of service dollars are spent on out-of-home options. Consequently, providing families with comprehensive support services would require either additional

resources and/or re-allocation of existing funds. Given a scarcity of fiscal resources and significant pressure to maintain current allocation patterns, many are reluctant to support further development of family support programs. In fact, some claim that it makes little sense to allocate additional resources for a service (i.e., family care) that is already being provided at no public cost. On the other hand, proponents of family care argue that all parties would benefit if the family were provided with needed services and point out that even a small decrease in family efforts would confront legislators and taxpayers with enormous financial burdens. From this perspective, it makes programmatic and fiscal sense to promote rather than ignor family efforts.

Socio-Demographic Trends One socio-demographic trend that bears watching pertains to the increased role of women in the work force. Because the primary caretaker is more often female than male, trends indicating that more and more women are pursuing employment suggests that in the future there will be fewer potential caretakers to provide long term intensive care in the family home. Likewise, the increasing number of single parent families and the tendency for families to be smaller than in the past may also signal fewer family caretakers in the future.

Administrative Uncertainities Establishing an effective state wide family support program is a complex political and programmatic task. As a result, state officials often approach the challenge with caution which in turn has meant that family support initiatives have developed very slowly around the country. Among the issues that must be resolved are:

- What state department(s) or division(s) related to human services should administer the program?
- How many families have memnbers with disabilities living at home and what are their characteristics and level of need?
- What families should be eligible (equity)?
- How should services be dispensed (cash subsidy, voucher, support services, or some combination)?
- What funding resources should be tapped (federal, state, county)?
- What role should the private sector (businesses) play?
- What services should be permissible?
- What limits (if any) should be placed on the amount of services provided per family?
- How much will the program cost today and in the near future?
- How should scarce fiscal resources be divided among various service modalities including family support programs, community based systems, and institutions?

Objective 2: To identify new approaches for encouraging families to plan financially for the future of their relatives with disabilities.

Every parent wonders, at some point in his or her child's life, "what will happen to my child if I die or am permanently incapacitated?" In most instances the response depends on the age of the person with disabilities and family situation. Parents normally expect that as their offspring approaches adulthood, s/he will be competent to manage his or her personal and financial affairs. For parents, of persons with developmental disabilities, however, responsibilities do not necessarily diminish with the passage of time. Unique issues must be faced to protect and maintain the health, welfare and financial well-being of persons with disabilities for the duration of his or her life.

Approaches to coping with this problem can be encompassed under the term "financial planning." Financial planning refers to the means by which parental assets can be placed at the disposal of their offspring with disabilities after the parent's death. Findings related to this second project objective are as follows:

1. Financial planning often is beyond the reach of many middle and low income families because they have insufficient capital to initiate individual plans;

2. For many parents, financial planning is problematic since mecahanisms such as Individual Retirement Accounts and many insurance policies require a significant investment and a concommitant reduction in available family income. In addition, joint ownership of property and other ways of transferring property and resources to the family member with disabilities may result in a change in the person's eligibility status for federal entitlement programs. As a result, programs specializing in financial planning services are emerging to help parents decide on the best means for placing resources at the disposal of their offspring with disabilities.

3. Carefully worded trust arrangements have gained popularity as an effective means of financial planning. Numerous types of trusts exist but the three most commonly referenced involve testamentary, inter-vivos, and master trusts. Master trusts hold special promise for low or middle income families. Because many financial institutions refuse to manage small trusts, many parents with limited income cannot easily arrange a trust. Master trusts, however, allow parents to pool a portion of their assets in the name of their son or daughter with disabilities with assets contributed by other parents. Consequently, these combined assets are managed as a single trust with each contributer maintaining control over his or her assets.

   Complementing this approach are programs offering life insurance or a death benefit naming the person with a disability as the beneficiary. At the death of the insured parent, proceeds are placed into a trust for the person with disabilities. If the life insurance premiums are reasonable, this tact may be of use to parents of low or middle income.

4. Based on national survey efforts, eleven financial planning programs were identified that provide systematic estate planning and/or trust arrangements for persons with developmental disabilities. These programs vary considerably but:

- most programs began in the late 1970's or early 1980`s;
- many also assume guardianship of the person with disabilities; and
- many also provide a range of other services including advocacy and information services;

5. Due to their recent inception, the long term efficacy of specialized financial planning arrangements is unknown.

Objective 3: To examine the fiscal incentives and disincentives that influence parental choices regarding the placement of family members with developmental disabilities and to identify innovative ways of countering incentives that favor out-of-home placement.

Examining factors that influence parental placement decisions is a complicated task made more difficult by its sensitive and personal nature. Our review of the literature and discussions at the conference, however, yielded the following findings:

1. The overwhelming majority of parents who have offspring with a developmental disability do not seek out-of-home placements. Instead, they choose to provide family-based care, often at great personal cost.

2. Among parents who seek out-of-home placements there is no one overriding factor that cuts across all families. Rather, there are numerous factors that vary from family to family. It is the combined force of existing factors that influences parental placement decisions.

3. Primary factors influencing parental placement decisions include:

   - Characteristics of the person with disabilities such as level of disability, IQ, age, functioning level, costs of care, and presence of behavioral problems;
   - Characteristics of the family such as family size, age of the parents, socioeconomic level, marital and family relations, and the presence of other family problems;
   - Perception of the problem as related to the level of stress family members experience. Such stress can be chronic and stem from a variety of sources including financial burdens, difficulty with physical management of the person with disabilities, lack of specialized care giving skills, and strained family relationships; and

- The absence of community services and social supports can exacerbate the severity of the problems experienced by families who provide long term care to members with disabilities.

4. Key factors that influence parental placement decisions do not necessarily remain constant. They change as the person with disabilities ages and as the family's composition, characteristics, resources, and perception of the problem are altered.

5. For many families at least three fiscal disincentives exist that contribute to present placement decisions including:

   - Extraordinary costs of health care. Numerous families are unable to acquire suitable health insurance for their family member with disabilities. Though public assistance is available to some under Medicare or Medicaid, the eligibility standards associated with these programs deny coverage to many families who need assistance in paying medical bills incurred by their member with disabilities. Likewise, private insurance is often inaccessible due to the high costs of premiums or because of a reluctance to offer coverage to persons with disabilities.

   - Specialized extraordinary costs that are necessary for maintaining the person with disabilities' health status, promoting skill acquisition, or for easing the caregiving burden. These costs can be related to purchasing special equipment, having housing adaptations completed, obtaining respite care, counseling related to having a family member with disabilities, or training on how to care for and instruct one's offspring with disabilities.

   - Opportunity costs incurred by family members. These costs often are related to a family member's employment status. Some parents must forego career advancement or any type employment in order to provide needed care in the home.

Given these considerations, it is clear that family support strategies must be flexible enough to meet the unique needs of families over time. Certain means for achieving this goal and eliminating the effects of the above noted disincentives have been enumerated throughout this summary. In essence, countering disincentives to family care is dependent on developing comprehensive systems of family support that blend public and private sector resources with state-of-the-art knowledge to provide family care givers and persons with disabilities the service array they require.

Recommendations

Findings emerging from this project reflect a growing understanding of the varying and complex needs of families, and the need to implement comprehensive strategies for satisfying such needs. Building an effective family support system, however, will require the cooperation of parents, immediate and extended family members, neighbors, government officials, and professionals working in the public and private sectors. Toward that end, these 13 recommendations are offered:

1. Family support programs should be designed to empower families and the person with developmental disabilities.
2. Family support programs should provide families with multiple service options.
3. Family support programs should make greater use of cash programs.
4. Family support programs should make greater use of options under the Medicaid program.
5. Family support programs should make greater use of private sector resources.
6. Using tax policy to support families should be pursued with caution, given a potential bias in favor of upper income groups.
7. Family support programs should make greater use of evolving computer technology.
8. Development of parent-led mutual help organizations that involve siblings and extended family members should be encouraged.
9. Family support programs should be designed to make greater use of existing resources and facilities.
10. Discussion should be encouraged between parents and professionals regarding unresolved conceptual issues.
11. A national study should be undertaken to identify the social and economic characteristics of families with members with developmental disabilities and to estimate their numbers.
12. A study should be made of sociological and demographic trends related to the family's caregiving capability.

13. Ongoing evaluations of family support programs should be made a high priority.

At the core of any effective family support system must be a firm societal resolve to actively encourage, rather than discourage, family care. Such a commitment is beginning to emerge and should, over time, replace past biases in social policy and professional judgements that favored out-of-home placement of persons with disabilities. This trend must be accompanied by a discussion of the respective roles that families, persons with disabilities, and government should play in directing the course of services.

In addition, the objectives of the move to support families should be clarified, the numbers of families in need should be determined, issues related to the administration and evaluation of statewide family support programs should be resolved, and all aspects of the community -- including the private sector -- should be involved in promoting family care. It is our hope that this report and the above recommendations will provide information and stimulate further discussion among those concerned with encouraging and enhancing family care.